

Outreach

2023

CONNECTING OUR COMMUNITY & RAISING AWARENESS ABOUT AUTISM

LONG ROAD HOME

Canadian family treks 2,000
miles for Parent Training

Page 30

PROGRESS IN PRESCHOOL

Community School provides
foundation for success

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RESEARCH HELPS ADULTS

Original research program
aims to improve skills,
quality of life

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Kicking into

HIGH GEAR

Robert Arvayo received a later autism diagnosis at age 7, but
JumpStart® got his family on the right track

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J A B U R G W I L K

L A W F I R M

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SARRC- a leader in understanding, treating, and improving the lives of people with autism, through innovative programs and research initiatives.

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On the Cover: Robert Arvayo
PHOTOGRAPHY: CARL SCHULTZ



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GIVING OUR GRANDSON HIS VOICE

Our grandson found his voice about a year ago and we attribute it all to SARRC's team. We feel so lucky that he, who was just 2 at the time, was enrolled at SARRC only six weeks prior to the COVID shutdown. Had it not been for SARRC providing full-time, one-on-one, in-home therapy for the next year and a half, he would not be where he is today, a happy and thriving little boy. Thank you so much for all you have done for him and for all you continue to do for the autism community.

-Janie and Jim



CREATE A VALUED CULTURE

There is a unique culture within the SARRC organization. Everyone we connected with is not only knowledgeable and informative, but I also truly value the warm and kind personal nature of the special people within your organization.

-Dan

"JumpStart is such a gift to this community! Thank you for continuing this program and for making it more widely available."

-Michele



"We have belonged to the Grandparents Support Group for a very long time. The staff is so warm and caring. We love going there. Keep up the great work!"

-Franceska



"We had a BIG camp training weekend! Lots of work and tons of fun getting ready for the summer. A huge thank you to @southwestautism for doing amazing inclusion training for camp staff. Our team is ready to have the best summer ever!"

—@hubbardswim

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Southwest
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2023 • Volume 17

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to the writers, editors, photographers
and designers who contributed in-kind
time and service to SARRC.



MESSAGE FROM THE PRESIDENT & CEO

IMAGINE...

BY DANIEL OPENDEN, PH.D., BCBA-D

At SARRC, we do a lot of “imagining” when it comes to crafting our goals and vision for the future. I like to think that we’ve far exceeded what our co-founders first imagined when they started SARRC more than 25 years ago. But we cannot rest on our successes, so we continue to imagine.

Imagine... SARRC expanding from four to nine campuses in Arizona with new locations in the East and West Valleys, North Phoenix, Tucson, and Flagstaff. Each campus will be anchored by an inclusive SARRC Community School, which enrolls just as many typically developing students as it does children with autism. Every day, those typically developing students are learning how to meet children with autism halfway by welcoming, supporting, including and interacting with their peers with autism. You can read the story of how Levi and his family’s lives were changed by their Community School experience on page 32.

Imagine... every child with autism is identified and diagnosed by 2 years old. One in 36 children have autism, yet the average age of diagnosis in Arizona is nearly 5 years old. At SARRC, we are making strides to improve early access to care. In a study funded by the National Institutes of Mental Health, SARRC partnered with 110 pediatricians who agreed to universally screen all patients at 12, 18 and 24 months. As a result, the age of diagnosis was lowered to 22 months, giving children about three more years of treatment.

Our cover story in this issue (see page 26)

shares the story of Robert, who was 7 years old when he received his autism diagnosis. As a spectrum disorder, when you have a child who is extremely verbal like Robert, it’s easy for parents, teachers and pediatricians to dismiss the possibility of autism.

Fortunately, at SARRC, we have programs like JumpStart® that provide critically needed information, support and strategies to help families succeed. In JumpStart, Robert and his family received one-on-one, customized coaching with a licensed Board Certified Behavior Analyst® (BCBA) to provide a better understanding of autism as well as new strategies and tools they can use to help Robert thrive.

Imagine... removing barriers to care for families facing an autism diagnosis all over the world.

Imagine receiving an autism diagnosis for your child in the middle of the pandemic, and facing a cycle of waitlists while watching your child continue to struggle. Imagine being a family who receives that diagnosis while residing in a rural community in Ontario, Canada, where resources were limited even before the pandemic. Then... imagine finding SARRC.

That’s the story of the LaPlante family, who embarked on a 2,000-mile journey so that Lucas and his family could attend our comprehensive One-Week Parent Training program. You can read about their incredible journey on page 30.

All of this can and hopefully will be a reality one day because we are addressing the challenges we face today and imagining what’s possible tomorrow.

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SARRC Welcomes 3 New Board Members



Lorrie Hochuli | Hochuli Design and Remodeling Team, Principal Designer & Co-founder

Lorrie Hochuli is the principal designer and co-founder of Hochuli Design where she works side-by-side with her husband since 2001 designing and remodeling homes throughout the Valley. She has had a passion for autism awareness and research ever since her youngest daughter was diagnosed with autism in the fall of 2015. Since her daughter's diagnosis, Lorrie has sat on various committees with Autism Speaks and SARRC, while also having assisted other families whose children have been diagnosed with autism.



Marc Isaacs | Retired Company Executive & Community Volunteer

For 19 years, Marc was the president and CEO of Sun Orchard, LLC, where he remains an investor and board member. Currently, he is the board member and former board chair for St. Mary's, one of the nation's largest and oldest existing food banks. Marc also serves on the Arizona Diamondbacks Foundation's Executive Council. Marc's family involvement with autism awareness and research has increased over the years as his daughter is a member of SARRC's Self-Advocate Advisory Board. Additionally, his son, Adam, and his wife founded PAL Experiences Inc., a nonprofit focused on providing resources to families who have been impacted by communicative disorders, such as autism spectrum disorder.



Charles Markle | Greenberg Traurig, LLP, Shareholder

Charles Markle is a shareholder at Greenberg Traurig, LLP, where he focuses on areas such as contract disputes, breaches of duties, provisional remedies, and condominium termination transactions. A graduate of Arizona State University's Sandra Day O'Connor College of Law, Charles has successfully tried cases before juries and judges alike, made successful arguments before the Arizona Court of Appeals, and obtained favorable rulings for his clients from the 9th U.S. Circuit Court of Appeals.

BOARD ACHIEVEMENTS

TOM HARRIS

- Honored with the "Tom Harris Field" in his hometown of Winslow, Ariz., by the Arizona Diamondbacks Foundation

DENISE D. RESNIK

- Selected as a Virginia G. Piper Charitable Trust 2022 Class of Piper Fellow

DR. CHRISTINE WILKINSON

- Honored as a "Women of Achievement" by *In Business Magazine*

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Beloved SARRC Staffer Retires

If you've ever attended a SARRC event, you have undoubtedly spotted a 5-foot-2 spunky woman zipping around mobilizing volunteers or directing traffic. You may also see her giving inspirational tours and presentations or happily greeting visitors at one of our campuses.

This is Addie Mocca, a well-seasoned veteran employee who has dedicated 19 years of service to SARRC.

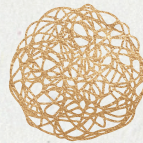
Addie has grown alongside SARRC since 2004 when she was the 12th hired staff member, serving in countless roles but always serving as the anchor of SARRC's development team. She has pivoted and adapted throughout her tenure and has been an invaluable asset.

Addie has contributed to four campus openings; two capital campaigns; the establishment of one of SARRC's most coveted programs, the Grandparents Support Group; hundreds of events, including serving as the face of Operation Santa Claus for SARRC; and

the list goes on.

She has helped grow what SARRC has become today: a talented team of more than 200 employees armed with a dynamic community of dedicated volunteers. SARRC would not be Arizona's leading nonprofit autism provider without Addie. She is without a doubt, one of SARRC's most beloved team members.

While Addie will be missed dearly, and there will never be shoes big enough to fill the void she will leave behind, we are immensely happy for her as she enters and enjoys the next chapter of her life. Cheers to you, Addie! You will always have a lifelong friend in SARRC.

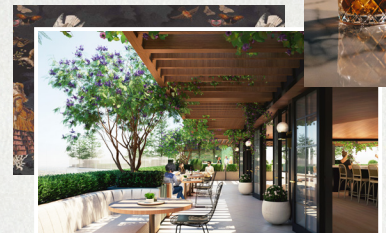


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Jennifer Burwell

Jennifer Burwell joined SARRC in 2023 as vice president of operations, a new role that oversees human resources, information technology, facilities and security, as well as client experience.

Burwell comes to SARRC with a robust background in organizational leadership and operations, with specific experience in real estate, including

residential properties, multifamily housing, industrial space and office buildings. She has a wealth of knowledge and experience overseeing large remodels, the purchase and updating of buildings, as well as managing information technology teams and projects. Her impressive background directly aligns with SARRC's strategic plan, organizational structure and plans for future growth.

SARRC Announces Vice President of Operations

EMPLOYMENT ANNIVERSARIES

15+ Years

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Hanna Roen
Haley Rose
Beth Salazar
Karen Scott
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Madison Theis
Julie Tyma
Maggie Wade
Eaugelique Ware
Deanna Whiting
Ashley Weaver
Amanda Winters

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Monique Auger
William Bassler
Christine Gomez
Jill Haglund
Brittani Harris

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Amy Clark
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STAFF ACHIEVEMENTS

KYLA BERNAL CHRISTENSON and **MADISON THEIS, BCBA**, presented on “Shifting Perspectives through Changing-Criterion Design” at the Arizona Association for Behavior Analysis’ annual conference.

STEPHEN JAMES, PH.D., and **NICOLE MATTHEWS, PH.D.**, presented original SARRC research at the annual meeting of the International Society of Autism Research (INSAR) in Austin, Texas.

HANNA ROEN, BCBA, and **KATRINA WARRINER, BCBA**, presented on “Relational Frame Theory: Practical Applications for Direct Service and Supervision” at Arizona Association for Behavior Analysis’ Acceptance and Commitment Therapy and Relational Frame Theory Special Interest Group’s March 2023 meeting.

HANNA ROEN, BCBA, was elected an Arizona Association for Behavior Analysis board member.

DANIEL OPENDEN, PH.D., BCBA-D, was honored as a 2022 Phoenix Titan 100, which recognizes Phoenix’s Top 100 CEOs & C-level executives, for his leadership and diversity within the Phoenix business community.

PAIGE RAETZ, PH.D., BCBA-D, presented on “Employment Supports and Community Engagement” on behalf of the Council of Autism Service Providers.

CHRISTOPHER J. SMITH, PH.D., and **NICOLE MATTHEWS, PH.D.**, published “A mixed-methods examination of the gap between intelligence and adaptive functioning in autistic young adults without intellectual disability” in the peer-reviewed journal *Autism: International Journal of Research and Practice*.

CHRISTOPHER J. SMITH, PH.D., **NICOLE MATTHEWS, PH.D.**, and **MELISSA MITCHELL** published “A qualitative examination of the impact of the COVID-19 pandemic on children and adolescents with autism and their parents” in the peer-reviewed journal *Research in Developmental Disabilities*.

CHRISTOPHER J. SMITH, PH.D., and **STEPHEN JAMES, PH.D.**, published “Implementing the Get SET Early Model in a Community Setting to Lower the Age of ASD Diagnosis” in the peer-reviewed *Journal of Developmental & Behavioral Pediatrics*.

LAUREN SMITH, CFRE, is currently serving as president elect of the Association of Fundraising Professionals-Greater Arizona Chapter. She also graduated from Valley Leadership’s Catalyze Program, a leadership development program that explores Arizona’s most pressing issues and how to take action in the community.

KATRINA WARRINER, BCBA, was elected president of the Arizona Chapter of the Association of Contextual Behavioral Science.

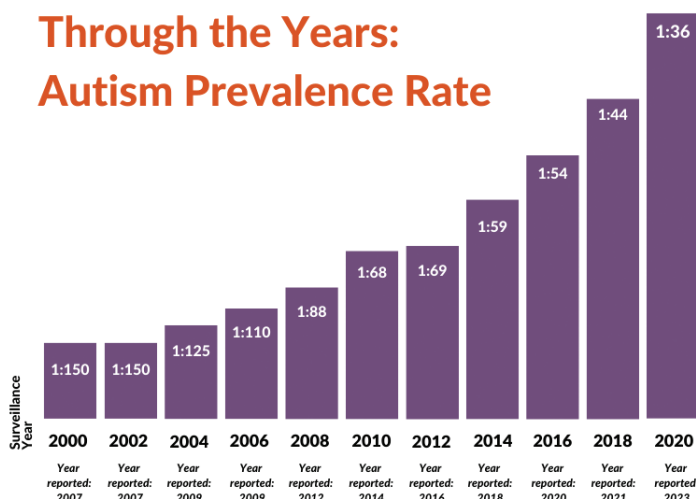
1 in 36: New Autism Prevalence Rate

In spring 2023, the Centers for Disease Control and Prevention released new data from the Autism and Developmental Disabilities Monitoring Network (ADDM) reporting that approximately 1 in 36 8-year-old children in the U.S. were identified with autism spectrum disorder (ASD) in 2020. This new rate is up from the reported 2018 prevalence of 1 in 44.

KEY FINDINGS:

- For the first time, Black, Hispanic and Asian or Pacific Islander 8-year-old children had a higher percentage of ASD than White children.
- Boys were nearly four times as likely to be identified with ASD as girls. However, 2020 marked the first time the ADDM Network found the percentage of girls identified with ASD to be over 1%.
- The median age of ASD diagnosis is 49 months nationally and 57 months in Arizona.

Through the Years: Autism Prevalence Rate



Autism prevalence in Arizona has nearly doubled since 2014, when the rate reported was 1 in 71 8-year-old children. Some good news is the percentage of children evaluated by 36 months increased from roughly one-third to 50%.

Read more at autismcenter.org/AutismPrevalence

Eagles Autism Foundation's Special Visit

Just prior to Super Bowl LVII, SARRC had the chance to host the Philadelphia Eagles' Eagles Autism Foundation and official mascot, Swoop. The foundation, which aims to make a meaningful difference in the lives of those affected by autism, visited the Campus for Exceptional Children to learn more about SARRC's programs and services.

During their visit, the foundation gifted SARRC with a surprise \$25,000 check in support of our programs, services and research initiatives.



22nd Annual Operation Santa Claus

Thanks to our friends at Sanderson Ford and Sanderson Lincoln as well as ABC15, SARRC has been a proud partner and charity recipient of Operation Santa Claus Charity Drive for the past 22 years. Throughout the holiday season, Sanderson Ford and Sanderson Lincoln hosted numerous events around the Valley to collect thousands of food items, toys and cash in support of participating charities.

Face of Individuality

Colliers in Arizona fosters a culture that inspires individuality. We believe every person is blessed with unique gifts and it is our job to encourage those talents in meaningful ways. This principle applies to our team members and the community at large. As we focus on changing the lives of people with neurological differences, let's nurture their individuality and celebrate their presence in our lives. What a gift.

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Former Arizona State Rep. César Chávez, SARRC Co-founders Denise D. Resnik and Dr. Raun Melmed and President and CEO Daniel Openden, Ph.D.

SARRC Receives Legislative Proclamation

Last year, SARRC Co-founders Dr. Raun Melmed and Denise D. Resnik, along with President and CEO Daniel Openden, Ph.D., paid a visit to the State Capitol to visit former Arizona State Rep. César Chávez who presented them with a legislative proclamation in celebration of SARRC's 25 years of service.

As a longtime supporter of SARRC, Chávez was inspired by the impactful stories shared at the annual Community Breakfast and he wanted to help raise awareness and acceptance for autism.

Eye-Tracking Device Receives FDA Clearance

In June 2022, EarliTec Diagnostics was the first to receive FDA clearance for the

EarliPoint™ Evaluation, a measurement tool that assists clinicians in diagnosing and assessing autism in children ages 16 to 30 months.

In 2018, SARRC was one of six research sites that tested the investigational device. The device works by

tracking the eye movements

of young children as they watch a series of short, age-appropriate videos and images, which helps determine if a child is missing key moments of social learning. The technology has been proven to assist in providing a safe, consistent and effective diagnosis while measuring a child's social disability and cognitive ability, making it the first objective diagnostic tool for providers.



SARRC Launches Employment Workshops

Entering the workforce can be daunting for teens and adults who don't have autism. To aid those who do, SARRC has introduced Employment Workshops, a new program to help individuals with autism explore their interests and abilities in a variety of settings while developing essential skills to establish and maintain employment.

Over a six-week period, participants will meet once a week in a collaborative group space with an instructor where they learn important work-related behaviors such as how to answer interview questions, communicate effectively in a workplace, develop resumes, and search for jobs.

For more information about SARRC's Employment Workshops, please contact SARRC's Family Resource Team today at 602.606.9806 or visit autismcenter.org/Employment-Workshops.





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Past SARRC Peer Mentor Selected for Rhodes Scholarship

Rhodes Scholar Shreyas Hallur first connected with SARRC as a Peer Mentor in our CommunityWorks® program, and after graduating high school and moving to North Carolina to attend Duke University, he continued to be involved with SARRC. In 2018, he initiated a grant proposal for a program aimed at creating inclusive science learning opportunities for autistic children, which resulted in SARRC winning a \$1 million grant from the National Science Foundation. Just this past summer, while home from school, he served as a SARRC research intern.

Having SARRC serve as a launching pad into his passion for policy and improving care for autistic people who have intense care needs through

shared decision-making, Shreyas continues to progress both as a student at Duke as well as a board director of a private school that has designed a novel, hands-on STEM curriculum to meet the educational interests of its autistic students.

This summer at Oxford University, Shreyas plans to pursue degrees in Medical Anthropology and Evidence-Based Social Intervention and Policy Evaluation for people on the autism spectrum, which he credits to his time with SARRC.



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Event Highlights

SARRC held its largest fundraising event, the Annual Community Breakfast, on April 14, 2023, welcoming nearly 1,500 attendees. The event featured personal stories from families, clients and community leaders.

The program highlighted current and past clients and families of SARRC, the latest happening in research as well as our clinical programs, and much more!

Funds raised during the event support SARRC's mission to

advance research and provide a lifetime of support for individuals with autism and their families.

Watch the entire 2023 event online on SARRC's YouTube Channel at youtube.com/SouthwestAutism.

2023 Annual
Community
Breakfast

Imagine

Annual YES Day for Autism



On October 23, 2022, SARRC held its second YES Day for Autism™ — a free event focused on raising funds, awareness and acceptance.

Held at Tempe Beach Park, the event featured a resource fair, pumpkin patch, carnival zone, as well as an array of live entertainment from celebrity personal trainer Chris Powell and special musical guest CG5. As part of our second annual YES Day for Autism, participants and sponsors helped SARRC exceed its goal of \$400,000.



SAVE THE DATE:
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OCTOBER 29, 2023
TEMPE BEACH PARK

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Leaving a LEGACY



SARRC'S LEGACY CIRCLE was established to create an endowment fund for the long-term needs for individuals with autism and their families. This circle of ongoing support was formed to honor some of our most loyal donors for their commitment to SARRC's mission.

To learn more about the Legacy Circle or upcoming events, visit autismcenter.PlanMyLegacy.org or contact Lauren Smith at 602.218.8213.



"Having had many medical issues, especially when I was very young, I'm fascinated by the science behind everything and I'm inspired by the autism research going on at SARRC."

– Zach Zaborny
SARRC Legacy Circle Member

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As a partner for more than 22 years, Blue Cross Blue Shield of Arizona has been key to furthering SARRC's mission of advancing research and providing a lifetime of support for individuals with autism and their families.

In May 2022, BCBSAZ's newly formed Foundation for Community & Health Advancement awarded SARRC with an applied research grant to study the effects of mindfulness-based interventions for reducing anxiety and depressive symptoms in adolescents with autism spectrum disorder and their caregivers.

Through this generous funding and collaborative partnership, our team is actively working to improve mental health and quality of life for adolescents with ASD and their caregivers.



The Steele Foundation Supports SARRC's Tempe Campus Growth

In December 2022, The Steele Foundation generously awarded SARRC with a grant to support our Community School program, an inclusive preschool for young learners ages 15 months to 5 years. Specifically, this funding will support our dedicated team of clinicians and teachers on our Tempe campus who lead 40 students across four classrooms.

This special funding has made an immediate impact to effectively grow our team now and for years to come..

The Steele Foundation, a private Arizona-based foundation, is focused on investing in children to educate, empower and enrich their lives. As our partner, we are grateful that The Steele Foundation recognizes and supports our work and steadfast commitment to providing inclusive and impactful educational opportunities for children with and without autism.

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SARRC's Multiyear Visionary Partner (MVP) program is an opportunity for annual donors to make a multiyear gift of five years or more that will be invested into our vital programs, services and research. MVPs are driven by a vision where people are meaningfully integrated into inclusive communities — empowered to make friends, learn, live and work in the community.



Multiyear Visionary Partner

Contact Maureen Jorden at
MJorden@autismcenter.org or visit
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Center for Children with Special Needs and Autism

The Center for Children with Special Needs and Autism, is a center designed to provide and coordinate support services needed by the families.

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Words to Live By



Here's a search of some of our favorite words.
Can you find all 12 of the **BOLD** words?

We are **proud** to **partner** with **SARRC** as they continue to advance **research** and provide **resources** for individuals with autism spectrum disorder and recognize their connection to our mission to be a family that uses our collective **superpowers** to do significant **good**.

At Master Electronics, we have an ongoing open dialog with employees who have children and **family** members with **autism**.

We recognize the unique challenges that our employees may face when caring for a family member with autism and are **thankful** to be able to support an amazing organization that helps us all **care** for our loved ones in the ASD **community**.

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Planning for the Future

BY EMILY B. KILE, ESQ.



I want to care for my child after I'm gone, but I was told by my lawyer not to leave any money in my child's name. Why is that?

Some parents decide to disinherit a child who is receiving government assistance due to a disability. However, there are some risks. What if you leave “extra” money to one child and that child uses the money or gets a divorce? The money you hoped would assist your special needs child might not end up where you intended. Instead, you can work with an attorney and have a special needs trust (sometimes called a supplemental care trust) established. A properly drafted special needs trust allows a trustee (of your choosing) to manage the funds for your child and will not impact the benefits the child is receiving (assuming the trustee follows the “rules” of a special need trust).

Why does a parent with an autistic child need a will?

Everyone should have an estate plan! However, your will can set up a special needs trust for your special needs child and set forth a successor guardian when you can no longer care for your autistic child. Having a will might not result in avoiding probate, but it will certainly help to ensure that the people you want to manage your assets after death go to the right place and protect a child who may need a guardian.

What is a special needs trust?

A special needs trust that is set forth as part of an estate plan allows you to pick who will manage the money for a person who is eligible for government assistance, retain those benefits and

yet still “inherit” money. The money (or other assets) are managed by the trustee named in the trust document but are there to enhance the life of the beneficiary. At the death of the beneficiary, the remaining assets can be distributed to the beneficiaries named in the trust. These are often referred to as “third-party special needs trusts.”

A special needs trust might also be needed if someone who is entitled to government benefits inherits money directly or receives the proceeds from a settlement or award from a personal injury matter. Those kinds of trusts have lots of rules and any money that remains in the trust at the death of the beneficiary must be paid back to any government programs that provided services. These are often referred to as “payback trusts” or “first-party special needs trusts” or “self-settled special needs trusts.” Setting up a third-party special needs trust as part of your planning is better than having the beneficiary needing a first-party special needs trust.

[Read the full FAQ at autismcenter.org/FuturePlanning »](https://autismcenter.org/FuturePlanning)



Emily B. Kile is an Arizona-based attorney with Kile Law Firm who practices in the areas of estate planning, guardianship and conservatorship, ALTCS planning, probate and trust administration and special needs planning. Visit kilelawfirm.com for more info.



Preguntas frecuentes: Planificación para el futuro

POR EMILY B. KILE, ESQ.

Quiero cuidar a mi hijo después de que me haya ido, pero mi abogado me dijo que no dejara dinero a nombre de mi hijo. ¿Por qué es eso?

Algunos padres deciden desheredar a un hijo que está recibiendo asistencia del gobierno debido a una discapacidad. Sin embargo, existen algunos riesgos. ¿Qué sucede si deja dinero “extra” a un niño y ese niño usa el dinero o se divorcia? El dinero que esperaba que ayudaría a su hijo con necesidades especiales podría no terminar donde pretendía. En su lugar, puede trabajar con un abogado y establecer un fideicomiso para necesidades especiales (a veces llamado fideicomiso de atención suplementaria). Un fideicomiso para necesidades especiales debidamente redactado permite que un fideicomisario (de su elección) administre los fondos para su hijo y no afectará los beneficios que recibe el niño (suponiendo que el Fideicomisario siga las “reglas” de un fideicomiso para necesidades especiales).

¿Por qué un padre con un niño autista necesita un testamento?

¡Todo el mundo debería tener un plan patrimonial! Sin embargo, su testamento puede establecer un fideicomiso para necesidades especiales para su hijo con necesidades especiales y establecer un tutor sucesor cuando ya no pueda cuidar a su hijo autista. Es posible que tener un testamento no resulte en evitar la sucesión, pero sin duda ayudará a garantizar que las personas que desea que administren sus activos después de la muerte vayan al lugar correcto y protejan a un niño que puede necesitar un tutor.

¿Qué es un fideicomiso para necesidades especiales?

Un fideicomiso para necesidades especiales que se establece como parte de un plan patrimonial le permite elegir quién administrará el dinero de una persona que es elegible para recibir asistencia del gobierno, conservar esos beneficios y aun así “heredar” el dinero. El dinero (u otros activos) son administrados por el Fideicomisario nombrado en el documento del Fideicomiso, pero están ahí para mejorar la vida del beneficiario. A la muerte del beneficiario, los activos restantes pueden distribuirse a los beneficiarios nombrados en el Fideicomiso. Estos a menudo se denominan “fideicomisos de terceros para necesidades especiales”.

También se puede necesitar un fideicomiso para necesidades especiales si alguien que tiene derecho a los beneficios del gobierno hereda dinero directamente o recibe las ganancias de un acuerdo o adjudicación de un asunto de lesiones personales. Esos tipos de fideicomisos tienen muchas reglas y cualquier dinero que quede en el fideicomiso a la muerte del beneficiario debe devolverse a los programas gubernamentales que brindaron los servicios. Estos a menudo se denominan “fideicomisos de recuperación” o “fideicomisos de necesidades especiales de primera parte” o “fideicomisos de necesidades especiales autoestablecidos.” Establecer un fideicomiso para necesidades especiales de un tercero como parte de su planificación es mejor que hacer que el beneficiario necesite un fideicomiso para necesidades especiales de un tercero.

[Lea las preguntas frecuentes completas en autismcenter.org/FuturePlanning »](https://autismcenter.org/FuturePlanning)

Original SARRC Published Research

Study Demonstrates Ability to Lower Age of Autism Diagnosis

Findings from the study “Implementing the Get SET (Screen, Evaluate and Treat) Early Model in a Community Setting to Lower the Age of ASD Diagnosis” were published in the *Journal of Developmental & Behavioral Pediatrics*, a peer-reviewed journal focused on providing resources for professionals in the field of pediatric healthcare. The Get SET Early model was designed by researchers at the University of California San Diego to screen, evaluate and treat autism within the first two years of life.

A previous study demonstrated that when delivered through a university-based research program, the Get SET Early model lowered the average age of ASD diagnosis to 19 months. To determine if similar results could be replicated in a community-based setting, SARRC’s research team followed Get SET Early guidelines by developing a network of 109 pediatricians in the Greater Phoenix area who agreed to screen at 12-, 18- and 24-month well-child checkups using a validated screening tool. Toddlers identified as having developmental delays by the screening tool were referred to SARRC for an evaluation where trained licensed psychologists provided diagnostic evaluations. Families were provided with rapid referrals for treatment when appropriate.

During a four-year period, over 45,000 screens were administered, and 648 children were evaluated at SARRC. The median age for ASD diagnosis overall

was 22 months, which is significantly lower than the median age of diagnosis in Arizona (57 months) reported by the CDC. Two-thirds of children diagnosed with ASD were enrolled in a treatment program. Taken together, these results suggest the Get SET Early model was an effective strategy for improving the current approach to screening, evaluation and treatment referral for toddlers with ASD.

Understanding the Experiences and Needs of Children with ASD During Pandemic

When the world shut down due to the COVID-19 pandemic, SARRC’s team was acutely aware that individuals with ASD and their families may be disproportionately impacted by public health measures like stay-at-home orders and telelearning. To better understand their experiences and to inform planning for future emergency events, SARRC began a year-long survey study.

In 2022, SARRC researchers published the first journal article from this study, titled “A Qualitative Examination of the Impact of the COVID-19 Pandemic on Children and Adolescents with Autism and Their Parents,” in the peer-reviewed journal *Research in Developmental Disabilities*. Parents who participated in the study reported that public health measures associated with the pandemic led to new challenges for their child with ASD but also unexpected gains, like the development of daily living skills. Abrupt changes in functioning were reported by many parents, including potential skill regressions, increased challenging behaviors and increased mood



LEARN MORE ABOUT RESEARCH FINDINGS

Did you know that SARRC’s research team publishes easy-to-read summaries of original research publications? To read SARRC Research Briefs, visit autismcenter.org/sarrc-research-briefs

symptoms. Several protective factors were identified, like continuity of educational and intervention supports, access to environmental resources, and child adaptability and perseverance.

Together, findings suggested that families of children with ASD may benefit from increased supports to both recover from the COVID-19 pandemic and to prepare for future emergency events. Additional supports may include increased flexibility across educational and clinical services, parent/caregiver training, and public supports for low-income and marginalized populations.

You're Invited: Research Open Houses



SATURDAY, JUNE 10 • 10 A.M. TO NOON
SATURDAY, NOV. 4 • 11 A.M. TO 1 P.M.

Research participation and medical procedures (e.g., bloodwork, physical, vitals) can be a new experience for many families. SARRC's Research Department hosts Open Houses for families and community members to learn about research opportunities and become familiar with study-related medical procedures in a low-pressure environment. Attendees participate in a behind-the-scenes tour, meet our research team and participate in mock medical procedures. Light refreshments are served. Join us at an Open House Event in 2023!

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Hitting the Ground Running

For the Arvayo family, a delayed diagnosis for their son Robert meant lost time to help him get the support he needs. But thanks to SARRC's JumpStart® program and their own diligence, Robert is thriving.

By Ginger Scott

Photography by Carl Schultz

At first, Ellen and David Arvayo considered their son Robert's grit and determination to be qualities of a competitive kid. Robert wasn't a quitter, and he didn't like to lose. Sometimes it was learning to ride his bike and repeatedly getting up after falling. Other times heightened emotional reactions to losing youth soccer games. But when those behaviors started to seep into the rest of Robert's life, Ellen and David started to wonder if something more was going on.

Robert was first diagnosed with ADHD, which fit some of the signs he was showing, but not all the behaviors his parents were noticing. That's when the Arvayos were referred to SARRC, and Robert was diagnosed with autism at the age of 7.

"We were shocked because we didn't really understand the spectrum part of autism, and we were convinced he didn't have autism because he was extremely verbal," Ellen recalls. "We had many misconceptions of autism. But when we received the diagnosis the greatest feeling we had was relief. We could now help him, and it brought us hope."



Robert
Arvayo



Robert and David Arvayo

“JumpStart® gave us focused tools to help us with Robert. It gave us a lay of the land so we could understand where we were and where we needed to go.”

~Ellen Arvayo

ENTER JUMPSTART®

With an official diagnosis in hand, the Arvayos were able to enter SARRC’s JumpStart program, though they were at the top of the age range that the program serves (children younger than 8). JumpStart is a six-week program that helps families who are new to autism by providing important information, support and strategies from a licensed Board Certified Behavior Analyst® (BCBA) for customized coaching sessions. There was definitely some ground to be made up, but the Arvayos and SARRC were determined and ready to learn.

“Research always says early intervention is key to best possible outcomes, which made Ellen feel discouraged that she missed out on early help for her son. But she was determined,” says SARRC Senior Clinical Consultant Brittani Harris, BCBA, who guided the Arvayos family through SARRC’s JumpStart program. “She came to the program enthusiastic in wanting to learn how to support her child.”

For Robert, now 8, it was learning how to navigate through transitions – ending a game or stopping an activity – as well as verbalizing his disappointment differently. Rather than getting upset when he loses a game, Harris taught the Arvayos to encourage and practice other reactions, such as saying, “good game” or “I need a break.”

As with all SARRC programs, the approach to intervention is individualized for each client and family. Harris was careful to involve him in discussions about strategies and challenges as well as how to include him in conversations on how to best support his needs and wants. Usual behavioral therapy techniques were also tweaked to better fit Robert’s unique needs. Harris says JumpStart coaches aim to tailor sessions to each child and their parent(s) and caregivers based on their communication needs. For example, rather than language learning, for Robert, it was a matter of learning the right words for specific situations.

These lessons were brought home, and the entire family went to work to put the tools into practice. Ellen describes the family’s time with JumpStart as a lifeboat.

“We were floating at sea afraid of drowning, not knowing what to do, how to be with Robert, how to treat him or work things out with him,” she says. “JumpStart gave us focused tools to help us with Robert. It gave us a lay of the land so we could understand where we were and where we needed to go.”

PARTNERING WITH PROVIDERS

Closing the gap between diagnosis and intervention is one of SARRC's priorities. To support this mission, SARRC offers training on evidence-based screening practices that are easy to execute and encourages pediatricians to screen for developmental delays starting at 12 months, which is six months earlier than the screening ages recommended by the American Academy of Pediatrics.

"We believe it is critically important for all healthcare providers, but especially pediatricians, to recognize the importance of early identification and early intervention for autism. It is also important that they recognize the need for a formal diagnostic evaluation sooner rather than later," says Christopher J. Smith, Ph.D., SARRC's chief science officer.

When a screening questionnaire indicates concerns, Smith says, parents should be referred for a developmental evaluation because only a formal diagnosis will open the door to evidence-based treatments.

"Delays can be subtle and may not cause any problems for parents in day-to-day lives, so the general inclination is to wait until they do," Smith adds. "That leads to lost time in the early developmental time period when intervention can do the most good. If parents act on subtle differences and seek an evaluation, they will get more definitive information about their child's delays from experts who know what to look for and then advise them appropriately. Parents have nothing to lose by pursuing an evaluation. If they don't agree with the results, then they can put it in a drawer until they are ready. Nothing happens automatically as a result."

MAKING UP TIME

For the Arvayos and their son, time has been of the essence. And the family has worked hard to help their son make strides. Learning that Robert's frustrations and outbursts weren't simply tied to him being a perfectionist but rather that he perceives the world differently gave his parents a better understanding of how to help him.

"We have just begun our journey," Ellen says, excited about the future. "The most significant changes we have seen are with challenging behaviors. Because JumpStart gave us focused help with the most immediately needed behaviors, we have been able to navigate his challenging behaviors and get him motivated and turned

around a lot more quickly. We have learned where to give and where to stand firm so we can help him to get and stay on track with tasks, schoolwork and activities."

And seeing this renewed confidence in parents is what Harris likes most about her work.

"I love what I do. I've been doing it for 13 years at SARRC. The bigger thing – as much as I love seeing progress with my clients – is the parents. We gather information on the parents' confidence and knowledge before they start JumpStart and at the end of their participation. When you see those scores change from pre-service to post-service, that is it! You can actually see the confidence in these parents. They go from feeling unsure of where to go and what to do, to knowing they've got the tools to navigate their child's diagnosis." ▶

Ellen and Robert Arvayo



Inspiring Destination

LaPlante Family Makes 2,000-Mile
Journey to Find Support at SARRC

BY MARK FABERY



PHOTOS COURTESY OF THE LAPLANTE FAMILY

The LaPlante family, hailing from Niagara-on-the-Lake, a small farming community in Ontario, Canada, faced challenges finding resources for their 4-year-old son Lucas after receiving his autism diagnosis in 2021.

Lucas, who was in preschool at the time of his diagnosis, was having difficulty communicating his needs and was becoming increasingly frustrated at home and in the classroom. The family was caught in a cycle of waitlists until they learned about SARRC from a family friend whose grandson attended SARRC's One-Week Parent Training — one of two formats offered to families, depending on their schedule and location.

"Our friends couldn't say enough great things about SARRC and the services they provide, and their grandson is flourishing," Lucas's grandmother Leah says. "With Lucas receiving his diagnosis during the pandemic and the long waitlists, we decided that SARRC was where we wanted to be."

LaPlantes head south

As a result, the family packed their bags and embarked on a 2,000-mile journey to SARRC, so Lucas and his mom, Michelle, could attend the One-Week Parent Training. This short-term program teaches strategies and equips parents to support their child's social-communication development through hands-on practice. Additionally, the program's one-week model allowed the family to learn all of the strategies that are offered in the 12-week format.

"The program features two formats that allow families living outside Maricopa County, out of state, or even out of the country to access effective strategies that can be applied to their child's natural environment while being coached by a clinical consultant," says Brittani Harris, BCBA, a SARRC senior clinical consultant.

While working with their consultant at SARRC, the family had several goals in mind for Lucas, including appropriate ways to increase his responsivity, requesting attention, initiating interactions, and engaging with others at home and in the classroom.

Tools for improvement

The LaPlantes credit SARRC with providing invaluable tools and resources to help Lucas better communicate with his family, teachers and peers.

"It was so beneficial to work with our clinicians as they answered all our questions, and they gave us a lot of opportunities to use the skills we learned while they were in the room. We were praised and coached on the use of the new skills, as they set us up for success when we went back home," Leah says.

She adds, "The program has given us the tools to bring out the best in Lucas and made us realize that he can be successful if we put the time in and utilize the tools we learned to help him be the best that he can be. Since the program, Lucas has been initiating playtime and has learned the correct ways to get our attention and to use his voice."

Not only has Lucas shown progress at home, but his teachers have also seen positive growth in his behavior.

"His school has seen a lot of improvement, and Lucas now calls all of his teachers by name and is starting to call the other students by their names as well," Leah shares.

Through the strategies learned from SARRC's One-Week Parent Training, the LaPlante family looks to continue supporting Lucas on his autism journey by utilizing the tools they learned. ▶



LEARN MORE

SARRC's Parent Training program equips parents with strategies to help teach their child appropriate social and play skills that will benefit their child and their family throughout a lifetime. Through coaching by a Board Certified Behavior Analyst (BCBA) and hands-on practice, parents learn about naturalistic and effective practices.

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For more information on SARRC's Parent Training program, visit autismcenter.org/ParentTraining or call 602.606.9806.

Community School helps family overcome challenges,
find success in general education classroom

Rising Above

BY STEPHANIE JARNAGAN



SARRC COMMUNITY SCHOOL®

Now Enrolling!

Do you have a child age 15 months to 5 years who is ready for a high-quality preschool program? Benefits of the Community School:

- Small class sizes
- Highly educated and enriching team
- Play-based, developmentally appropriate curriculum focused on school readiness
- July-June school year
- 3 campuses: Phoenix, Tempe, Scottsdale

For more info, contact our Family Resource Team at **602.606.9806** or visit autismcenter.org/CommunitySchool

When Lauren LaBelle's son, Levi, was around 9 months old, she began to have concerns about his behaviors. He seemed overly sensitive to loud noises and new people frightened him.

"He also wasn't responding to his name at all, and his reactions seemed more intense and extreme than normal," LaBelle says.

Her concerns continued to grow as Levi began demonstrating social anxiety, preferring to play independently instead of engaging with other kids, and struggled with breaking from routines.

LaBelle had a co-worker whose daughter was diagnosed with autism, and she recommended looking into SARRC. LaBelle did so, and decided to enroll Levi in a SARRC clinical research trial for toddlers aimed at improving early detection of autism through the use of an investigational device that tracks eye movements of young children. Part of the research included SARRC's traditional diagnostic process, and that's when Levi received a diagnosis of autism at 26 months.

"After that, I knew I wanted to get Levi into SARRC's Community School because my co-worker's daughter had a very positive experience in the program," LaBelle says.

Enrolling in the Community School

SARRC boasts three Community School campuses in Maricopa County that offer a high-quality early childhood education to children ages 15 months to 5 years.

"The cornerstone of this unique program is that inclusion is embedded in the core of everything we do," says Beatriz Orr, clinical director of the SARRC Community School. "Children who are neurotypical and those who have a diagnosis of autism are learning alongside each other without knowing who has autism and who doesn't. They are all learning compassion and acceptance — something we hope they will carry with them for a lifetime."

After enrolling in the Community School in early 2019, Levi had a really hard time entering the preschool building. His fear



of new people and places had to be overcome, so SARRC's team of therapists got to work devising creative ways to manage his hesitations using wagon or scooter rides to encourage him.

"Their compassion and the effort they put into making him feel more comfortable made a huge difference for us," LaBelle says. "It took many months for him to overcome this challenge and then COVID hit, and everything changed for him again."

Navigating Setbacks

Although the Community School did not operate in-person during the height of the pandemic, Levi continued to receive services from a therapist five days a week for six to eight hours per day.

"He had a SARRC therapist, Caley, from his Community School class who was like an extended member of our family. She worked on goals with him in our house, and he continued to progress. His vocabulary developed, he improved his eye contact and he got better at handling transitions," LaBelle says.

When the Community School reopened, he had an easier time adjusting and was able to play and communicate with the other children.

"I love the model because there are kids with

and without autism learning together," LaBelle says. "There is so much that all kids can learn from this program socially, emotionally and academically. They also have an extremely low child-to-teacher ratio, which is something you just don't get at other preschools."

Orr agrees and is quick to point out how the program benefits all children, even those without autism. "Our Community School teachers support and guide all students during challenging situations to build coping, problem solving and social communication skills all in a positive, empathetic and supportive way. Every child has individual strengths and areas for growth, so our teachers individualize their support for each student to meet them where they're at."

Today, Levi is enrolled in a general education kindergarten class and he's thriving. According to Orr, that's a goal that many families in the Community School achieve with various levels of support.

"I always knew he was going to be successful," LaBelle says. "No matter what, I knew he was going to rise above this because we got him the help he needed." ▶

Building Skills for

Brighter Futures

Supports for adults with autism can be hard to find, but an original SARRC study aims to bridge this gap by equipping adults with valuable tools to strengthen skills and ultimately improve quality of life

BY KAREN SCOTT

Since his teen years, David F. inherently knew he was different and always suspected autism. It wasn't until he went on a trip with his family in 2021 that he found it more challenging than ever to navigate a new routine and environment.

"When you're not able to do something and you feel like you can't do it because of who you are and something you can't change, it hurts a lot," David, 32, shares.

The family vacation was David's tipping point. He yearned for answers, so he took the initiative to find support. He searched the internet for programs that specifically supported autistic adults in the Phoenix area. While he didn't yet have a diagnosis of autism, his search led him to SARRC's website where he consequently called the team and received some options.

Strengthening Skills Research

At the time, SARRC's Director of Research Nicole Matthews, Ph.D., was leading a new research study designed specifically for autistic adults. David was an ideal candidate.

Aptly named Strengthening Skills, the program — part of an overarching research study —

would teach strategies for strengthening executive skills, mindfulness-based emotion regulation and interpersonal relationships.

"This study was a result of an ongoing collaboration that we have with Blair Braden, Ph.D., director of the Autism and Brain Aging Lab at Arizona State University, and Leslie Baxter, Ph.D., clinical neuropsychologist at Mayo Clinic Arizona," says Matthews. "Many years ago, we embarked on a study of brain aging in autistic adults. Through that work, we identified several unmet needs in this population. Preliminary findings suggest increased vulnerability to age-related cognitive decline and ongoing challenges with social relationships and mood symptoms."

While David had not yet received a formal autism diagnosis when he inquired with SARRC, his experiences, challenges and barriers with social communication made him a viable candidate to participate. Many individuals with autism go undiagnosed until adulthood and it can be very challenging to receive a formal diagnosis as an adult. For this reason, a formal





David, pictured below, participated in SARRC's Strengthening Skills program, which was specifically designed for autistic adults and conducted remotely during the pandemic.



diagnosis was not required to participate in the study. Instead, participants were administered multiple assessments, including the gold-standard observational measure for autism, to determine whether they demonstrated symptoms consistent with ASD and qualified for the study.

Ultimately, David was enrolled to participate in the Strengthening Skills program, which was awarded funding in late 2019 by the Department of Defense Autism Research Program. Despite the pandemic, the study moved forward via videoconferencing technology from August 2021 to March 2023.

The researchers were able to adapt what was intended to be an in-person program to something that could be delivered through telehealth. In addition to overcoming obstacles presented by the pandemic, this allowed the research team to connect with many participants who otherwise may not have been able to participate because they lived too far away to attend in-person group meetings.

“Beginning in 2021, we enrolled 42 adults between the ages of 21 and 73, with an average age of about 41 years. Participants were randomly assigned to participate in either Strengthening Skills, an adapted version of PEERS®, which is a social skills program for young adults with autism, or a delayed treatment control group (i.e., they completed a 10-month wait period while we collected data and then went through Strengthening Skills),” shares Matthews.


Targeting Healthy Habits

Under the guidance of the researchers, participants focused on developing healthy habits that, if practiced consistently, can make a meaningful difference in their day-to-day lives. Adults in the group and their program partners each identified an area in their own life that they wanted to work on.

Continued on page 37

A silver Ford Mustang Mach-E is shown driving on a dirt road, with a blurred background of mountains and a clear blue sky.


THE ALL-ELECTRIC
FORD MUSTANG MACH-E


SANDERSONFORD.COM
PROUD SUPPORTER OF SARRC

“Participants chose activities like exercising, meal planning, staying on top of their laundry or managing email,” shares Matthews. “We taught basic steps to define, plan and track new habits with the ultimate goal of helping adults realize that they can establish new habits that will make their lives easier.”

The team collected data about participants’ adaptive functioning, quality of life and mood symptoms before they went through the program, at the end of the program, and at three- and six-month follow-ups. They also collected data regarding their perception of the strengths and limitations of the program.

“Our entire team is very proud of the novelty of this program. There are literally no evidence-based programs available for autistic adults past young adulthood,” says Matthews.

She shares that the lack of support makes it challenging for adults like David who receive a late diagnosis.

Not only did the mindfulness aspect of the program help David learn how to manage and regulate his emotions, but the communications skills he gained helped him advocate for himself in the workplace.

David’s professional background has primarily focused on customer service and political canvassing roles, environments that he has adapted to and enjoys despite executive and social skills challenges.

“The program taught me how to speak up on these issues and communicate effectively as well as advocate for accommodations, and the tools to help me find people with common interests,” shares David. “I didn’t realize how overwhelmed my senses were. I would come home from work and would be so stressed. And couldn’t sleep.”

David admits social relationships are still a challenge, but he’s working on them and applying the principles he learned as a participant. “The program has given me the tools to help me find people with common interests and to find those meaningful relationships that I probably wouldn’t have had before.”

Analyzing Research Findings

The research team finished delivering the program to their last group in March 2023 and is currently analyzing data to learn if the program was effective. However, preliminary findings from the first two groups suggest that autistic

adults and their program partners found the program to be helpful, and most participants would recommend it to other autistic adults.

“I receive email updates from past participants about how they are using a particular strategy they learned in the program in their lives many months later. That epitomizes our end goal,” Matthews says. “We wanted adults who participated in the program to gain effective strategies to continue to improve their day-to-day lives long after the program ended.”

While the study has concluded, Matthews and her team have big plans for the future. “It is our hope that this will be the first of many studies that will focus on supporting autistic adults and improving their quality of life.”

Additionally, the team looks forward to presenting preliminary findings from the study at the annual meeting of the International Society for Autism Research in May 2023 and plans to publish all findings from the study in a peer-reviewed journal.

“I did receive a formal autism diagnosis after participating in the study, which has provided clarity. I can take constructive steps and there are resources that can help me. I can move forward with my future,” David says.

He looks forward to serving on a new advisory committee made up of past Strengthening Skills participants to share his perspective on the study findings and next steps for the program.

“I want to be a part of helping people like me,” David says. “The world is missing out on so much from older adults who have autism and aren’t necessarily the best at communicating, but there is so much amazing talent and ability and insight and wonderful things (in them).”

“We wanted adults who participated in the program to gain effective strategies to continue to improve their day-to-day lives long after the program ended.”

~Nicole Matthews, Ph.D.
SARRC Director of Research

Learn more about services at SARRC for adults at autismcenter.org/teen-adult-services

Greater Phoenix Housing Market Analysis sheds light on invisible housing crisis

BY DENISE D. RESNIK

The First Place Global Leadership Institute Make Waves Center for Community Development recently released the 2022 Greater Phoenix Housing Market Analysis (GPHMA), the first-ever study to address the housing needs and preferences of adults with autism and/or other intellectual/developmental disabilities (A/I/DD).

The comprehensive report helps make this too-often invisible population more visible — and their voices heard. It provides data to drive a more neuro-inclusive local housing supply, recognizing that current housing in Greater Phoenix cannot meet the financial, physical and cognitive needs of adults with A/I/DD.

The research process educated self-advocates and their family members or caregivers on potential options, collected data on their needs and preferences, identified barriers to meeting demand and explored how public, private, nonprofit and philanthropic sectors can work together on market solutions. In the coming year, the Make Waves Center will conduct four additional regional housing analyses in the U.S.

Housing is financially out of reach for most adults with A/I/DD. The National Low Income Housing Coalition estimates that to have lived in the Phoenix metropolitan area in 2022, a person must have earned \$43,640 annually to afford a one-bedroom apartment or worked 66 hours a week at minimum wage. According to the Arizona Developmental Disabilities Planning Council, despite a desire to work, only about 25% of adults with any disability are employed in Maricopa County.

Without housing options, this population lives with family members until a crisis forces rushed placements or even homelessness. The consequences are both traumatic for the individual and their family — and expensive for our state and communities. A lack of housing options too often prevents the neurodiverse population from moving beyond their original homes as integrated, contributing members of society.

More than 160 people, 20 of whom speak Spanish and 24% of whom are self-advocates, participated in the survey from August to September 2022. The study examined housing in Phoenix, Mesa, Glendale, Scottsdale, Tempe and Surprise. Bank of America, Make Waves Family Foundation, Stardust Foundation and Dominion sponsored the study. The GPHMA report is available online in English and Spanish at firstplaceaz.org/phx-housing-analysis.

The report builds on the 2020 trisector-led report published by First Place, Madison House Foundation and ASU's Morrison Institute for Public Policy introducing a new narrative for housing development. A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities (APITW) established foundational nomenclature for housing and service delivery models to further define market segments, establish best practices and guiding principles, and continue driving crucial partnerships addressing the current housing crisis.

"Nearly 160,000 adults in Arizona with A/I/DD need supportive housing," said Maureen Casey, director of the Centers for Applied Research and Public Policy at the Global Leadership Institute. "That's three times the size of Chase Field. In addition to building more housing options for the two-thirds waiting in the parking lot, we need to make sure that those needing access to long-term supports and services are in the right seats!"



Denise D. Resnik is founder and president/CEO of First Place AZ, co-founder of SARRC and mom to an adult son with autism.

Superhero Rising

BY BODIE BERNOSKY

Every superhero has an origin story, this is mine. I am a warrior, student leader, autism advocate, swimmer and a great friend! SARRC helped me come out of my shell. I now believe in myself and I see my future and it is shining bright.

In 2008, I was diagnosed with autism at age 2. My parents were not quite sure what to do but were determined to find help. One day, my dad heard a local radio station doing a campaign called “Action for Autism” benefiting SARRC. He made a mental note and reached out to SARRC shortly thereafter to find out how our family could get involved.

A short time later, in August 2008, I was enrolled in SARRC’s Community School program. When I first started at SARRC, I didn’t speak or make eye contact with anyone. The amazing team started early intervention services and got me speaking for the first time. By 3, I was a rather unstoppable chatterbox; I haven’t stopped talking since 2009! In May 2023, I will be on stage singing in front of a live audience for the first time ever. I have SARRC to thank for giving me my voice.

I know that SARRC changed my life. Every day I’m grateful for everything they taught me. I learned not only to talk but to follow the lead of a typical peer role model, a lesson I continue to use to this day. My first peer role model was my sister, and I remember my teachers at SARRC coming to the house to work with me and my sister and teaching both of us how to work together. It was through SARRC that I learned how to reach out, introduce myself, and make a new friend – a highly valued skill in the autism universe. As a result, I now have more friends in my inner circle than ever before! I am thriving thanks to SARRC’s methods and lessons that I keep in constant circulation in high school as I continue on my path to being my best self.

At school, I am a curious, sports-loving Gateway Warrior who loves NFL Football (especially the Cincinnati Bengals). I am proud to be a three-time Geography Bee champion and an emerging singer. I have a giant friend group of



PHOTO COURTESY OF BODIE BERNOSKY

happy-go-lucky, smart and caring individuals who bring me joy, happiness and pride to be who I am every day. Outside of school, I love swimming, playing soccer, creative writing and playing with my beautiful rascalions of a dog pack.

SARRC has taught me that when you surround yourself with amazing, loving, caring, inclusive souls with high spirits you really can soar. There are so many incredible people at SARRC who helped me get to where I am today. I hope my story is one that can inspire others to soar to the same magical heights.

Bodie Bernosky, 16, is a junior at Gateway Academy and has been part of the SARRC family since he was 2.

154,771
clinical
intervention
hours provided
to children,
teens and
adults with
autism and
their families



1,170
individuals
with autism
served through
clinical and
research
programs



19,204
parents, family
members,
typical peers,
teachers,
medical
professionals
and community
members
received
education and
training



1,963
students were
screened using
a validated
tool for use
in schools to
help effectively
identify school-
age children
with social
challenges



251
individuals
served through
Diagnostics
Services, the
first step on
the right path
toward effective
intervention



2022

SARRC COMMUNITY IMPACT



170
parents and
caregivers
attended Family
Orientation,
a free resource
to families at
any point
in their
journey



297
individuals
participated
in SARRC
research
studies
and
programs



125
children with
and without
autism attended
SARRC's
Community
School® program
across three
campuses



3,712
phone calls
were fielded
by SARRC's
Family
Resource
Team



55
young
children and
69
family members
participated
in JumpStart®,
a program for
families new
to autism

Programs, Services and Research

SARRC's clinical model is grounded in Applied Behavior Analysis (ABA) with a particular focus on naturalistic behavioral interventions in inclusive environments, including but not limited to: in the home, in school, on the job or in the community. Each of SARRC's therapeutic programs, classes and trainings are guided by best practice models; the most currently available science; increasing independence and producing meaningful outcomes; and the individualized needs of the children, teens, adults and families we serve.

Additionally, SARRC frequently works with educators, healthcare professionals, employers and other community partners to help maximize goals as it relates to supporting individuals with autism. Our outreach efforts can be individualized or offered in a group format, and they are listed under Community Services. All trainings and events promote the use of evidence-based interventions and strategies.

Unless otherwise noted, for more information on a program, service or research study, please contact SARRC's Family Resource Team at 602.606.9806 or visit autismcenter.org.

Para hablar con alguien en Español llame al 480.603.3283.

GETTING STARTED

EASY ACCESS AUTISM SCREENING*

The Easy Access Autism Screening program offers parents or caregivers the opportunity to address concerns about their child's development through a free screening assessment over the phone in 10 to 30 minutes. An experienced staff member will complete the interview, which is designed for parents or caregivers of children ages 12 months to 36 months. To schedule a screening, call 602.218.8204 or email EZscreen@autismcenter.org.

**Disponible en Español.*

DIAGNOSTIC SERVICES*

Our staff of licensed psychologists and skilled technicians have expertise in diagnosing autism in individuals ages 7 and younger. The resulting diagnosis for all clients is based on the criteria for autism spectrum disorder according to the Diagnostic and Statistical Manual, Fifth Edition (DSM-5). The process begins with a developmental history interview completed by phone with a parent or caregiver. Then, our assessment includes the Naturalistic Observation Diagnostic Assessment (NODA), a smartphone-based system that lets parents record and send videos to our staff for analysis in advance of the on-site evaluation.

**Disponible en Español.*

FAMILY ORIENTATION

Family Orientation connects caregivers of individuals with ASD to current and broad information that will help them navigate the journey of autism. Participants will learn about issues relevant to their child's stage of life. Orientations are for families with newly diagnosed children, those who have recently relocated to Arizona, and families making life transitions. Family Orientations are held once a month for caregivers of individuals in each age group: Young Child (younger than age 6), School-Age Child (age 6-12), Teens and Adults (age 13+). Orientations are free and delivered online.

MILESTONES PROGRAM

The Milestones program offers services and support for parents of infants starting as young as 6 months and continuing through 18 months of age. This program is ideal for families with infants who have an older sibling with a diagnosis of autism, as well as new parents looking for more information and support regarding their infant's development. Services include 1) evidence-based information on developmental milestones and parenting practices, 2) consistent monitoring and 3) a very early intervention option for babies demonstrating early signs of ASD or with a diagnosis of ASD prior to 18 months.

JUMPSTART®*

JumpStart® is designed for families of young children waiting for a diagnostic evaluation or report, those who have been recently diagnosed or those at risk for ASD. This is a six-week, entry-level program that provides information, support, training and tools that parents and caregivers will need to navigate autism today and tomorrow. Parents will receive one-on-one coaching and learn strategies to immediately address their child's social communication skills and challenges.

**Disponible en Español.*

COMPREHENSIVE,
LONG-TERM INTERVENTION

THINK AUTISM®

The Think Autism® mobile app is designed for parents, educators, pediatricians and other community stakeholders to consider ASD when they notice subtle social challenges in school-age children. Through the free mobile app, users can access a screening questionnaire, resources and a way to connect directly with SARRC. The Think Autism mobile app can be downloaded for free by searching “Think Autism” via the App Store or Google Play.

COMMUNITY SCHOOL®

SARRC’s Community School is an inclusive preschool program that provides intensive, ABA-based programming for children with ASD and high-quality early childhood education for typically developing children with campuses in Phoenix, Tempe and Scottsdale. All children (ages 15 months to 5 years) receive the benefits of highly trained SARRC therapists with a 4:1 student-to-teacher ratio; a play-based, developmentally appropriate curriculum that is aligned with state education standards; and a language-enriched environment structured to specifically improve meaningful engagement and social communication. Children with ASD also receive 1:1 intervention in the classroom, parent-training sessions conducted in the family’s home and in the community, and program supervision from a BCBA. After-school care is available for typically developing children.

COMPREHENSIVE BEHAVIORAL PROGRAM

SARRC’s Comprehensive Behavioral Program provides intensive, ABA-based programming across environments to meet the needs of children with ASD up to age 14 and their families. Treatment is primarily implemented in the home and in the community and is often coordinated with a student’s school. Families receive weekly 1:1 intervention sessions, regular caregiver training sessions, and program management and supervision from a BCBA. Goals are developed in coordination with the family and focus on increasing socially significant behaviors and highlighting each child’s individual strengths.

PROGRAMAS DE SARRC EN ESPAÑOL



El modelo clínico de SARRC utiliza el Análisis Aplicado de la Conducta (ABA por sus siglas en inglés) con un enfoque particular en intervenciones naturalistas en ambientes inclusivos, incluyendo pero no limitados al hogar, la escuela, el trabajo o la comunidad. Cada uno de los programas de SARRC se estructuran con prácticas basadas en la evidencia para aumentar la independencia y en última instancia, producir resultados significativos para nuestros clientes y sus familias.

- Servicios de intervención temprana
- Servicios enfocados de corto plazo
- Servicios para niños
- Servicios para adolescentes y adultos
- Tratamiento conductual Intensivo
- Servicios de diagnóstico
- Servicios familiares
- Servicios comunitarios

Para más información en Español, por favor contacte al equipo de admisión de SARRC al 480.887.0784 or visit autismcenter.org/espanol



Southwest
Autism
Research &
Resource
Center

FIRST PLACE® TRANSITION ACADEMY OPERATED BY SARRC

In partnership with First Place AZ®, SARRC's Transition Academy is a two-year program that provides comprehensive ABA-based programming to support transition for adults with ASD. Students live in apartments within the community while attending classes and working. Students receive a comprehensive curriculum, including career education and support, independent living skills, social and leisure skills, and transition services. The Transition Academy includes a 32-course sequence, consisting of classes on finances, interpersonal relationships, advocacy and personal safety, all completed at the GateWay Community College campus (or virtually during pandemic). Instruction is also provided within the students' apartments applying the skills they learn in the classroom to the natural environment.

INDIVIDUALIZED SERVICES

SARRC's Individualized Services is designed for teens and adults and delivers ABA intervention across environments to meet the needs of clients and their families. Services are implemented in a variety of settings which may include in the home, at work or within the community. Services are individualized, and goals are developed in coordination with clients and their family. Services are supervised by BCBAs and implemented by highly trained clinicians. We also offer parent training to support the transition into adolescence or adulthood.

COMMUNITYWORKS®

CommunityWorks® is a pre-employment program for teens with and without ASD to volunteer throughout the community while developing job, social and communication skills. Volunteer community locations vary by season and are primarily in the greater Phoenix area.

EMPLOYMENT WORKSHOPS

Employment Workshops provide an active space for teens and adults to develop a plan of action for securing employment. Over six weeks, participants will meet weekly in a collaborative group space with an instructor. Employment Workshops are best for those who are motivated, enjoy participating in a small group and desire immediate employment.

PARENT TRAINING

Parent Training offers two options: a 1-week and 12-week model. Together, parents and coaches will collaborate to identify individualized and meaningful goals. Parents will walk away with strategies that will benefit their child and family. Through coaching and hands-on practice, coaches will work alongside parents to target their child's language, social, play and adaptive skills in everyday routines and interactions.

PEERS® for Adolescents

PEERS® for Adolescents is an evidence-based social skills program for families with teens in middle and high school who are interested in making and keeping friends. Teens and parents will attend weekly group sessions. The teens will learn through instruction, role-play with coaching and group-based activities. Parents will attend a parent-group session that complements and directly supports their teen's learning.

PEERS® for Young Adults

PEERS® for Young Adults is an evidence-based social skills program for adults who are interested in making friends or developing relationships. Young adults will attend weekly group sessions and will learn through instruction, role-play and activities. It is strongly recommended that young adults enroll with a social coach that can be a parent, friend, roommate or sibling. Social coaches also attend a social-coach group session that complements and directly supports learning for the young adult enrolled in the program.

SECOND GEAR

Second Gear is an 8-week parent training program for families with a child between 4 and 10 years of age. Parents learn strategies for managing behavior at home by meeting with a BCBA a couple of times each week without their child and once a week with their child. During meetings, parents and coaches identify strategies for their child and family, and develop a plan for reducing challenging behaviors. During the parent coaching sessions, parents put the plan into action with their child and their coach by their side.



Progress (and a patent)

A new treatment for autism created by ASU Biodesign Institute researchers called Microbiota Transplant Therapy has been granted a patent – an important step toward developing an FDA-approved medication for treating core autism symptoms.

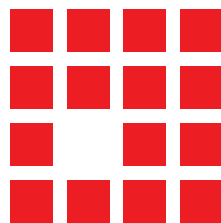
Srivatsan Mohana Rangan and Rosa Krajmalnik-Brown, left, work together in the Biodesign Center for Health Through Microbiomes.

ASU Arizona State University

biodesign.asu.edu

ARA

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A distinguished organization of 15 leading architectural firms that proudly supports **SARRC**

BE INSPIRED

www.ArizonaResidentialArchitects.com

Arizona Complete Health is proud to sponsor SARRC's Annual Community Breakfast!



We commend and celebrate SARRC for their leadership in autism research, treatment and outreach!

*"Transforming the health of the community,
one person at a time."*



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AzCompleteHealth.com



THE ARIZONA DIAMONDBACKS
ARE PROUD TO CELEBRATE
**SOUTHWEST AUTISM
RESEARCH &
RESOURCE CENTER!**



@DBACKSGIVEBACK #DBACKSGIVEBACK DBACKS.COM/COMMUNITY

OUTREACH

Outreach efforts include a variety of informational services to meet the needs of the professional, organization or community program, including brief presentations about autism and evidence-based practices, providing resources and materials about SARRC programs and services, or scheduling a tour.

EDUCATIONAL PRESENTATIONS

Educational presentations are delivered to provide information and messages with impact. Our consultants use stories, video examples, and interactive activities to engage the audience. Presentations can be customized and offered virtually or in the setting of your choice.

PROFESSIONAL DEVELOPMENT

Professional development opportunities are offered throughout the year at our Sybil B. Harrington Campus for Exceptional Children. Most events offer continuing education units for BCBAs.

STUDENT-BASED CONSULTATIONS

Student-based consultations include initial assessment to guide development of a proposal to meet the needs of the student, teacher, classroom and school. Initial observation and assessments are completed and reviewed with the school and include a variety of activities to meet the goals of the student and school.

INCLUSION TRAINING, CONSULTATION & PARTNERSHIPS

SARRC creates partnerships with local organizations committed to serving a diverse community. Training and consultation services are offered to school-based and recreational organizations that are moving toward or would like to improve upon an existing inclusive model to promote the success of all participants.

ARIZONA AUTISM EARLY DIAGNOSTIC NETWORK

The Arizona Autism Early Diagnostic Network (AAEDN) is comprised of pediatricians and psychologists committed to helping families who have concerns about their child's development and provides additional support if there are signs of ASD. This initiative is led by SARRC and focuses on shortening the time between an initial autism screening by a pediatrician and a formal autism diagnostic evaluation – the first step to early intervention and treatment. If you are a pediatrician or psychologist interested in joining the AAEDN network, contact us at 480.390.6559.

EMPLOYMENT PARTNERSHIPS

SARRC creates partnerships with local and national employers to increase competitive, community-based employment opportunities for adults with autism. Nationally, adults on the autism spectrum experience low rates of employment, but through the help of our valued Employment Partners, SARRC is committed to increasing employment rates among individuals with autism.

PHARMACEUTICAL TRIALS & RESEARCH STUDIES

SARRC is committed to identifying effective behavioral, educational and pharmaceutical treatment options for people with autism of all ages. Our research department maintains a robust portfolio of pharmaceutical research studies. See our website for the most current list of projects. If you are interested in learning more about participating in a study, please contact a member of our team at 602.340.8717. Learn more at autismcenter.org/research.

SNAPSHOT

Statement of Financial Position as of December 31, 2022 (unaudited)*

ASSETS

Current Assets	\$8,347,516
Long-Term Assets	\$14,803,878
TOTAL ASSETS	\$23,151,394

LIABILITIES

Current Liabilities	\$1,446,584
Long-Term Liabilities	\$448,780
TOTAL LIABILITIES	\$1,895,364

NET ASSETS

Without donor restrictions:	
Undesignated	\$10,861,384
With donor restrictions	\$10,394,646
TOTAL NET ASSETS	\$21,256,030

TOTAL LIABILITIES AND NET ASSETS	\$23,151,394
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Statement of Activities for the Period
Ending December 31, 2022 *(unaudited)

SUPPORT & REVENUE

Individuals & Corporations	\$5,503,740	24.5%
Grants	\$3,519,768	15.7%
Governmental	\$19,683	0.1%
Special Events	\$2,679,324	11.9%
Program Fees	\$11,944,834	53.2%
Interest, Dividend, & Investment	\$(1,302,837)	-5.8%
In-Kind Support	\$97,843	0.4%
Total Support & Revenue	\$22,462,354	100.0%

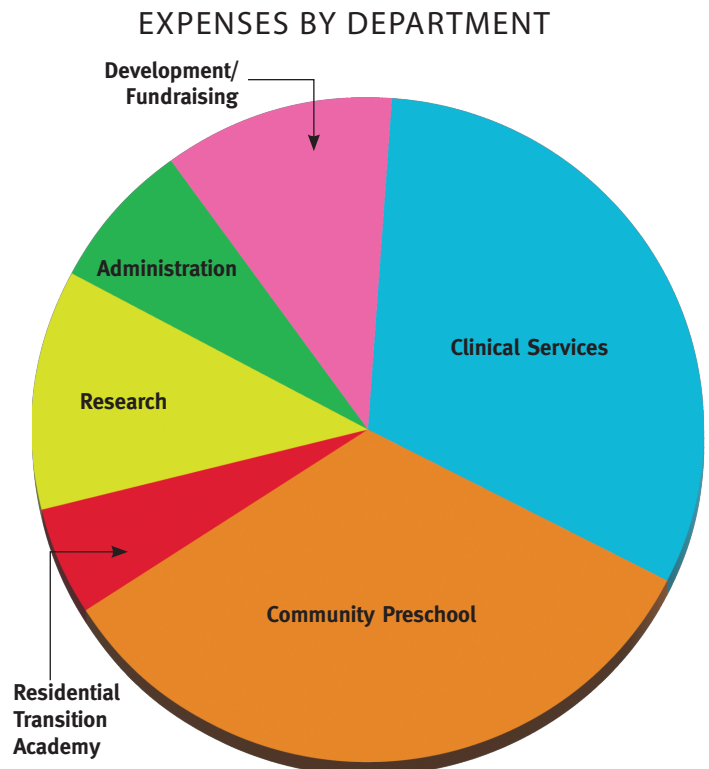
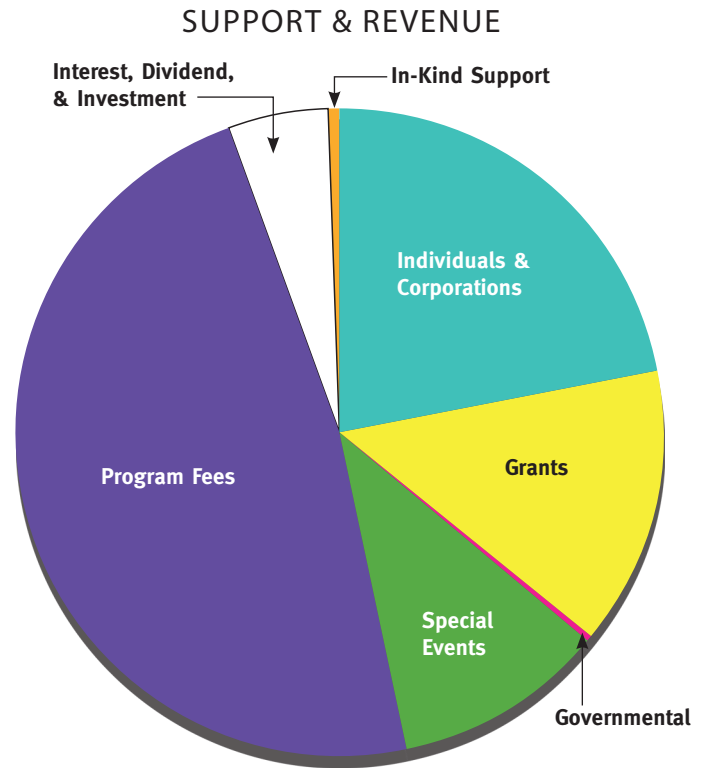
EXPENSES

Salaries, Benefits & Professional Development	\$14,071,877	75.7%
Contract Labor & Professional Services	\$821,789	4.4%
Program Expenses	\$1,851,493	10.0%
Postage, Printing & Marketing	\$117,069	0.6%
Occupancy & Communication	\$609,991	3.3%
Special Events Costs	\$381,707	2.1%
In-Kind Expenses	\$97,843	0.5%
Amortization & Depreciation	\$637,547	3.4%
Total Expenses	\$18,589,315	100.0%

TOTAL CHANGE IN NET ASSETS	\$3,873,040
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EXPENSES BY DEPARTMENT

Clinical Services	\$5,845,544	31.4%
Community Preschool	\$6,223,572	33.5%
Residential Transition Academy	\$962,937	5.2%
Research	\$2,154,484	11.6%
Administration	\$1,358,662	7.3%
Development/Fundraising	\$2,044,117	11.0%
Total Expenses by Department	\$18,589,315	100.0%



A copy of the fully audited financial statements will be available after June 30, 2023, by contacting Brian Shaw, Director of Finance, 602.340.8717.



OUR GOALS

The mission of SARRC's Grandparents Support Group is to empower grandparents through hope, education and support.

- **EMPOWER**

Through facilitated discussions, individuals gain insight, develop strength and find hope through shared experiences.

- **ENRICH**

Guest speakers and professional presentations provide key information on the latest research, therapeutic programs and resources available in the field of autism.

- **SUPPORT**

The Grandparents Group is here for you! By attending meetings, you will collect vital information, tips and strategies that will help your entire family on your autism journey.

GRANDPARENTS SUPPORT GROUP

Meetings are held monthly from October through May, with the goal of empowering, enriching and supporting all members. In addition to offering a network of support, grandparents attending the group's monthly meetings participate in facilitated discussions, learn the latest information about autism from guest speakers, receive advice and a chance to socialize.

View upcoming meetings online at autismcenter.org/events

CONTACT US

For more information, please contact our team at sarrc@autismcenter.org and 602.340.8717



SARRC

Southwest
Autism
Research &
Resource
Center

autismcenter.org/Grandparents-Group



Southwest
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SOUTHWEST AUTISM RESEARCH
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The Community School is an early childhood program focused on children 15 months - 5 years and offers high-quality education for young learners with and without autism — all in an inclusive classroom environment!

FEATURING

- 🔔 Small class sizes
- 🔔 4:1 student-teacher ratios
- 🔔 Individualized instruction
- 🔔 Play-based model
- 🔔 Three Valley locations

LEARN MORE

For more information on our admissions process, contact 602.606.9806 or visit autismcenter.org/communityschool



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